

**Patient-reported
Health Instruments
Group**

**Patient Involvement
and Collaboration
in Shared Decision-
Making: a review**

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Report to the Department of Health,
March 2005



health
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PATIENT-REPORTED HEALTH INSTRUMENTS GROUP

**PATIENT INVOLVEMENT AND COLLABORATION
IN SHARED DECISION-MAKING**

A STRUCTURED REVIEW TO INFORM CHRONIC DISEASE MANAGEMENT

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PATIENT-REPORTED HEALTH INSTRUMENTS GROUP

PATIENT INVOLVEMENT AND COLLABORATION IN SHARED DECISION-MAKING: A REVIEW

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Chapter 1: INTRODUCTION

a) Chronic disease

Defined as long-term conditions that can be controlled but not cured (Department of Health, 2004), chronic diseases account for 80% of GP consultations, 60% of all adults in the United Kingdom (UK) are diagnosed with at least one chronic disease, and 60% of all hospitalizations are due to chronic disease or exacerbations (Department of Health, 2004). The high proportion of health services devoted to chronic disease reflects the shift from acute to chronic illness as the major cause of health problems in the UK and suggests that finding ways to best serve chronically ill patients is among the most important challenges facing the health-care system.

b) New models of chronic disease management

Commonly called self-management programs, and exemplified by Dr. Kate Lorig's Chronic Disease Self-Management Program (CDSMP) at Stanford University in the United States, new models of chronic disease care have emerged in response to the challenge posed by rising rates of chronic illness. Although the details vary, most of the emerging models have a central theme of patient involvement in the health-care process. This paradigm of patient involvement has grown out of the recognition that:

1. Patients who live with chronic diseases must inevitably manage their condition (Bodenheimer et al, 2002; von Korff et al, 1997), and thus often become experts on the condition and how it affects their lives (Department of Health, 2001),
2. The successful control of chronic conditions depends upon patients' active participation in day-to-day regimens of medication, diet, and exercise (Heisler et al, 2003),
3. Whether or not chronically ill patients manage their disease well is a function of (among other things) their knowledge, management skills, and confidence in their management ability ('self-efficacy') (Heisler et al, 2003), and
4. The current health-care system was designed to treat acutely ill, and generally passive, patients over the short-term (Holman et al, 2000; Rothman et al, 2003). As such, traditional care has not fully tapped patient expertise as a resource, nor has it trained patients for their role as primary managers of their condition (Department of Health, 2001).

CDSMP and similar programs strive to utilize patient expertise and to support patients in their role as self-managers. Thus, patient involvement in the context of these 'self-management' programs taps patient expertise by helping patients to identify their problems, priorities, and preferences, and supports patient self-management by negotiating self-management plans with patients and training patients in problem-solving and coping skills.

This combination of patient priority identification and skills training is guided by the *patient-physician partnership paradigm* (Holman & Lorig, 2000), defined by Bodenheimer (Bodenheimer et al, 2002) as having the following two components:

1. *Collaborative care/patient empowerment*, or care in which providers are treated as experts in medical issues, while patients are seen as experts in their own lives and are encouraged to identify their problems and define goals, and
2. *Self-management education*, or education that provides patients with problem-solving and management skills for self-care of a chronic condition.

Bodenheimer's definition of the patient-physician partnership paradigm ('partnership paradigm') makes a distinction between patient collaboration in the consultation process (through information-provision, goal-setting, and decision-making), and patients' ability to undertake self-care activities. This distinction is echoed by other chronic disease care experts, so that *collaborative care* (Bodenheimer et al, 2002), *patient-centred care* (Lewin et al, 2001) or *collaborative management* (von Korff et al, 1997) are all defined as care in which providers work with patients to define and reach shared goals, negotiate decisions about interventions, and come to agreement about responsibility for management of the condition, while *self-management* or *self-care* can be defined as the activities a patient undertakes to control the symptoms and progression of chronic disease (Department of Health, 2004; Hibbard, 2003).*

Although both a collaborative care and a self-management education element are included in the partnership paradigm, it has not been determined whether these elements must be used in combination or if one or both is effective alone. Because it is unclear what components are the 'active ingredients', care models based on the partnership paradigm can be viewed as complex interventions as defined by the Medical Research Council (MRC). In 2000, an MRC panel advocated efforts to determine the necessary elements of complex interventions, stating:

It is essential to clarify as far as possible the important components, partly in order to devise protocols for [evaluative trials] and partly so that readers of eventual trial results can infer from results what elements were essential and what [were] secondary or unimportant in producing a beneficial effect (Medical Research Council, 2000, p.7).

Identification of vital intervention components is important in chronic disease care for a number of reasons. First, maximizing effective elements and minimizing unimportant activities will increase cost-effectiveness, allowing the health care system to cope more efficiently with the high prevalence of chronic disease. Second, 'chronic disease' is a set of diverse conditions that may respond differently to intervention elements. An understanding of the impact and interactions of various elements can help to guide optimization of interventions for individual conditions. Finally, distilling the most essential elements of a chronic disease care model enables health-care providers in various contexts to adapt the model to their needs without sacrificing its efficacy. In sum, clarifying the importance of the individual elements in an intervention is central to understanding *how* rather than simply *if* the intervention works, and thus enables wider, more efficient implementation and translation to other contexts.

* In contrast, *disease management* and *case management*, provided to a small proportion of all chronically ill patients, involves the provision of care by multidisciplinary teams and case workers (Department of Health, 2004).

c) Focus of the review

This review seeks to contribute to the understanding of how programs based on the partnership paradigm might improve the health of chronically ill people. To this end, and in light of the MRC's recommendation to explore individual components of complex interventions, the review focuses on the *collaborative care* element of the partnership paradigm. The reasons for this focus are twofold. First, a recent, comprehensive review of self-management education found mixed results (Warsi et al, 2004). Warsi et al evaluated the skills-education component of the partnership paradigm, but did not assess the impact of collaborative care on intervention effects. Second, a recent Cochrane review (Gibson, 2002) concluded that education alone does not improve health outcomes, and supports the findings that knowledge alone is poorly related to health behaviour (van Dam et al, 2003; Newman et al, 2004). This suggests that the success of programs modelled on the partnership paradigm is likely to be dependent on the inclusion of a collaborative care element. Supporting this theory, Bodenheimer reports that programs that involve patients in generating goals and action plans for asthma and arthritis self-management tend to be more successful than skills-education-only interventions (Bodenheimer et al, 2002). Similarly, Heisler finds in a cross-sectional study that patient collaboration in the consultation process increases patient adherence to self-management regimens, apparently by improving patient-provider agreement on problems and goals (Heisler et al, 2003); Heisler and Holman point out that patient adherence is a prerequisite for the success of self-management skills-training (Heisler et al 2003; Holman & Lorig, 2000).

This review thus conceptualizes collaborative care as a collection of potentially vital steps on the pathway between a chronically ill person's entry into the health-care system and improvement in his or her health status. More specifically, collaborative care will be defined for the purposes of this review as: *an interaction or series of interactions between a patient and the health-care system in which the patient is active in: providing information to aid diagnosis and problem-solving; sharing his or her preferences and priorities for treatment or management; asking questions; and/or identifying management approaches that best meet his or her needs, preferences and priorities.*

To evaluate the success of collaborative care interventions, the review includes randomized and non-randomized controlled trials. The review is limited to controlled trials because they are widely seen as being most appropriate for evaluating intervention effects (Evans, 2003; Sackett, 1997). Including a concurrent control group increases the confidence with which investigators can attribute changes in the intervention group to the intervention itself. This is especially true in randomized controlled trials where the process of randomization evenly distributes participant characteristics between the two groups, making them equal except for the intervention. In contrast, observational and before/after studies record changes over time, and cannot distinguish between intervention-dependent changes and changes that would have occurred regardless of the intervention.

Chapter 2: METHODS

a) Search strategy

A systematic approach was taken to retrieving references for the review. The primary search strategy ('main search') was designed to return intervention studies seeking to enhance patient collaboration (as defined in the previous section) in the health-care process. This search cast a wide net that allowed initial identification of a typology of interventions. Identification of this typology then allowed focused searches and/or reference to recent systematic reviews to retrieve additional studies within each intervention category.

Medline, accessed through Webspirs Silverplatter, was searched for the years 1977-2004. For the main search, terms related to 'intervention', 'collaboration', and 'outcome evaluation' were employed, as illustrated in table 1 below.

Table 1 Main search terms

INTERVENTION (Joined by 'OR')	COLLABORATION (Joined by 'OR')	OUTCOME EVALUATION (Joined by 'OR')
<ul style="list-style-type: none"> • Intervention* and patient and (communication or consultation or education) • Train* and communication • Skill* train* • Decision aid* • Checklist* • Prompt list* • Individualized measure* • Patient assess* 	<ul style="list-style-type: none"> • Communication and patient* • Consultation and patient* and participat* • Patient* concern* • Question* ask* • Action plan* • Goal set* • Individual* goal* • Share* decision making • Patient involv* • Patient participat* • Self manag* • ((Patient* or client*) near2 (clinician* or professional* or provider* or physician* or doctor* or nurse*)) near (communicat* or collaborat* or negotiat* or consult* or discuss* or dialog*) 	<ul style="list-style-type: none"> • Explode 'outcome-and – process-assessment-health-care'/all subheadings • (Evaluat* or effect*) and (intervention*) • (Patient or provider) and satisfaction • Self efficacy • Adherence • Compliance • Concordance • Health status • Quality of life

Informed by a typology of interventions identified in the main search, five secondary, focused Medline searches were subsequently undertaken to supplement the main search (patient-reported outcome measures, individualized measures, pain assessment, patient-held record, self-management). Tables of terms used for these searches are presented in Appendix I.

b) Inclusion criteria

Studies were included if they:

- Evaluated an intervention or model designed to increase patient collaboration (as defined in the introduction) in the health-care process,
- Focused on collaboration either explicitly (e.g., involvement was the intention of the intervention and/or was a measured outcome) or implicitly (as in the use of patient-reported outcome measures (PROMs) to increase patient information provision),
- Were controlled trials, and
- Included mechanisms of collaboration that were explicit and reproducible.

Articles were excluded if:

- The focus was on a paediatric population,
- The intervention was targeted toward medical students,
- The intervention outcomes were measured using hypothetical patients,
- The intervention was designed to involve individuals other than the patient, such as family members,
- The study focused on end of life or critical illness care,
- The intent of the study was to increase provision of information from provider to patient without evaluation of the impact on collaboration,
- Collaborative care was described as part of a wider intervention such as self-management education and was not specifically evaluated; i.e., it was not possible to disentangle the effects of patient involvement from the impact of other aspects of the intervention package such as education, or
- They were non-English.

One reviewer (SM) assessed all returned titles and excluded clearly irrelevant or duplicate items. Approximately 60% of the remaining titles were assessed by two reviewers (KH and SM) to check agreement. Borderline studies or disagreements about inclusion were resolved by consensus.

c) Data extraction

Data extraction was guided by a form designed for the purposes of this review. The form is presented in Appendix II, and is the result of numerous iterations undertaken to ensure that all relevant data were included. To check reliability, two reviewers (RF and SM) independently extracted data from six articles and checked agreement. Subsequently, data related to study design, characteristics of the population studied, specifics of the intervention, and results were extracted from the articles by all reviewers. Study results were reported as ‘positive’ (+) if a statistically significant ($p < 0.05$) difference between intervention and control groups was reported by the authors and the difference was in the expected direction. Results were reported as ‘no effect’ if there was no statistically significant difference between groups, and as ‘negative’ if a statistically significant difference between intervention and control groups was reported in the opposite direction to that expected. Data were subsequently entered into a Microsoft Access database designed specifically for the review.

Chapter 3: RESULTS

a) Search Results

The main search returned 3090 references from January 1977 to November 2004. Five distinct types of intervention that met the criteria for being collaboration-focused were described:

1. Patient-reported outcome measures/other questionnaires that increase the provision of information from the patient to the provider regarding problems or preferences,
2. Communication interventions (including written checklists, educational materials, and one-to-one coaching for patients, or communication skills training for providers) that encourage patient expression of problems, priorities, or preferences,
3. Patient-held records that allow patients to contribute to the information in their medical records,
4. Patient goal-setting, often in the context of a partnership paradigm-based self-management intervention, for behavior change or self-management, and
5. Patient values-clarification exercises, generally used as part of a decision aid, for identification of treatment or management approaches that best meet identified preferences and priorities.

The secondary searches based on this typology returned a total of 4442 titles, of which 35 were included. In addition to the Medline searches, reference lists of 8 systematic reviews (Espallargues et al, 2000; Fellowes et al, 2004; Gilbody et al, 2003; Greenhalgh et al, 1999; Harrington et al, 2004; Kruijver et al, 2000; Lewin et al, 2001; O'Connor et al, 2003) were searched, adding 29 articles. References of other relevant titles (Ruland, 2003; Velikova et al, 2004) were searched as well, adding five titles. Finally, PubMed's 'related articles' feature* was used with several key studies (Drury et al, 2000; Hershey et al, 2002; Velikova et al, 2004), and returned six titles that were included in the review. A table of titles returned, abstracts reviewed, full text articles retrieved, and articles included from each search is presented in Appendix III.

The review includes 146 articles representing 137 studies, 113 of which are randomized controlled trials, the remaining 24 being nonrandomized controlled studies. Appendix IV presents all included articles.

b) Study characteristics

The included studies were published between 1976 and 2004, with approximately half of the studies published since 1995. The number of studies meeting the inclusion criteria roughly increased over time (see figure 1), although this trend was not linear.

Fifty-eight percent of the studies were conducted in the United States, 20% in the UK, and the remaining 22% in various other countries, with Canada, Australia, and the Netherlands being the most prolific of these (see table 2). Forty-eight percent of studies occurred in a primary care or general medicine setting while 42% were conducted in a specialty setting and 10% occurred in the community or other setting.

Figure 1 Number of included studies published per year (1976-2004)

* The 'related articles' feature in PubMed allows the user to select an article of interest and search the database for articles with a high percentage of matching words in the title and abstract.

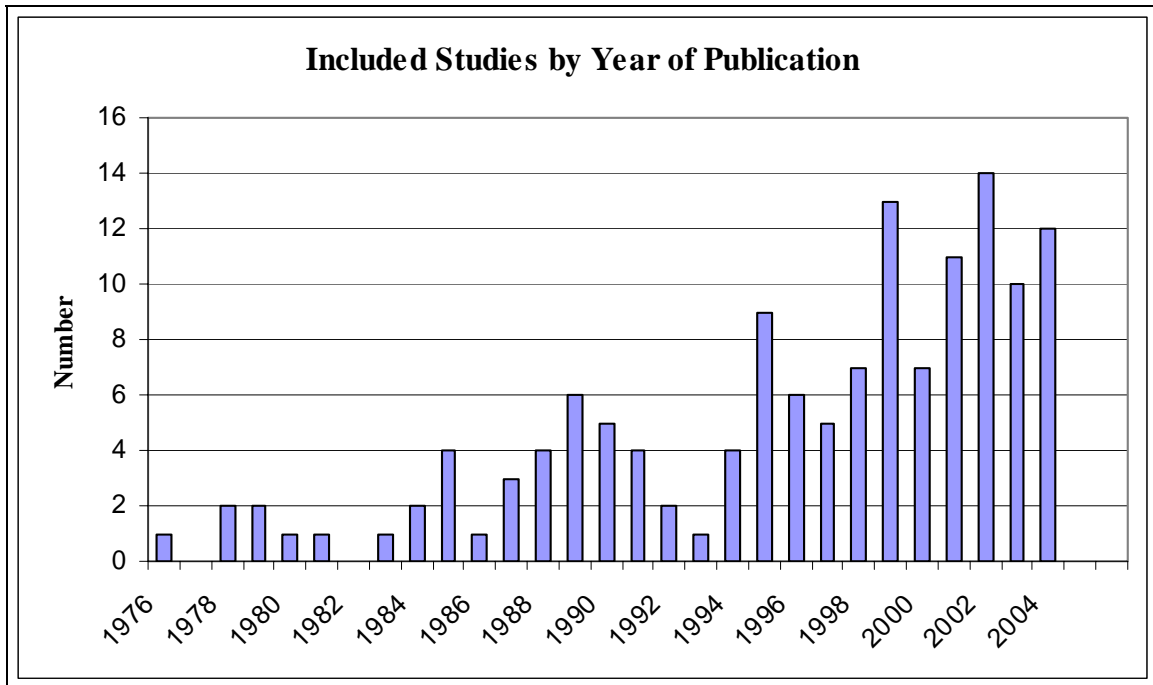


Table 2 Country settings

Country	N	%
<i>US</i>	79	58
<i>UK</i>	28	20
<i>Other</i>	30	22
Australia	5	
Belgium	1	
Canada	7	
France	2	
Germany	1	
Honduras	1	
Indonesia	1	
Mixed European	1	
Netherlands	5	
New Zealand	1	
Nigeria	1	
Norway	1	
Spain	1	
Sweden	1	
Trinidad and Tobago	1	
<i>All Studies</i>	137	100.0

Patient sample sizes ranged from 15 to 4941, with a mean of 351. Fifty-one percent of the participants in the study samples were female, and study participants had a mean age of 52.7 years. The patient group most often targeted was primary care/general medical populations with no specified diagnosis, followed by cancer patients. The proportion of studies focusing on various population groups can be found in Table 3.

Table 3 Patient population groups

Population	N	%
<i>Age Group (older people)</i>	8	5

<i>Cancer</i>	29	20
<i>Cardio</i>	7	5
<i>Diabetes</i>	10	7
<i>Mental Health</i>	16	11
<i>Mixed Chronic</i>	7	5
<i>Musculoskeletal</i>	3	2
<i>Neuro</i>	2	1
<i>Primary Care Population</i>	41	28
<i>Reproductive</i>	9	6
<i>Respiratory</i>	1	1
<i>Other*</i>	13	9
Total	146[†]	100

* 'Other' includes: risk factors (4 studies), acute care/self-limiting conditions (2), patients requiring occupational or physical therapy (2), patients undergoing surgery (1), patients with peptic ulcer disease (1), clients at a commercial weight loss programme (1), emergency care patients with symptoms 'likely to be associated with psychiatric illness' (1), and intellectually impaired adults (1)

† Because several studies included patients from two or more population groups, the total number of included population groups (146) is greater than the number of studies (137).

For 111 of the studies (81%), physicians were the health-care providers of interest, either as the target of the intervention or as the provider interacting with experimental and control patients. Only 11% of studies looked at nurses as providers of interest. Another 12% focused on allied health providers such as physician assistants or physiotherapists.

Data were extracted regarding study quality, with the initial intent of grading studies according to rigour. However, poor reporting of quality criteria made it impossible to ascertain how the studies were conducted. For example, sixty-three percent (71/113) of randomized controlled trials failed to report the method of randomization used, and 76% failed to note whether randomization was properly concealed. Only 25 of all 137 studies (18%) reported whether there were differences between participants that completed the study and those that did not. The reviewers determined that this lack of reporting made in-depth assessment of study quality unfeasible, since a poorly reported study might either mask a high-quality trial or reflect an overall lack of rigour. However, a broad comparison was made between the outcomes of well-reported and poorly reported studies. The results are presented table 4, and show that, at least in the short term (e.g. up to one week post-intervention), the proportion of positive outcomes appear to be inflated in the studies assessed by this review to be poorly reported or to have a lower level of rigour.

Table 4 Overall study outcomes by quality

Quality Measure	Results								
	Short-Term*			Intermediate*			Long-Term*		
	N	+ [†]	%	N	+	%	N	+	%
Study Type:									
• <i>RCT</i>	159	68	43	69	19	28	111	23	21
• <i>Non-RCT</i>	54	26	48	5	1	20	9	2	22
Randomization Method:									
• <i>Adequate method</i>	44	15	34	26	6	23	50	10	20
• <i>Method not reported</i>	111	50	45	43	13	30	61	13	21
• <i>Method not adequate</i>	4	3	75	0		—	0		—
Concealment of Randomization:									
• <i>Concealed</i>	36	13	36	15	2	13	30	6	20
• <i>Concealment not reported</i>	120	52	43	44	17	39	77	15	19
• <i>Not concealed</i>	5	3	60	0		—	4	2	50

*For the purposes of this review, 'short-term' applies to results measured immediately after the intervention up to one week post-intervention, 'intermediate' means two to 8 weeks post-intervention, and 'long-term' refers to those results measured 3 months or more after the intervention was completed

†Study results were reported as 'positive' (+) if a statistically significant ($p < 0.05$) difference between intervention and control groups was reported by the authors and the difference was in the expected direction.

c) Intervention characteristics

The 137 studies included a total of 152 intervention arms. The intervention arms included a total of 176 intervention methods (a single intervention arm could employ multiple intervention methods). One hundred thirty-nine of the intervention methods were targeted at the patient, while 37 targeted the provider (e.g. the physician, nurse or allied health professional providing care). Patient-targeted interventions included checklists, coaching, educational materials, goal setting, group education, patient-reported outcome measures (PROMs), other questionnaires, and values clarification exercises. Provider-targeted interventions included educational materials, prompt lists, and communication skills training. A description and example of each intervention method is given in table 5.

Table 5a Descriptions and examples of patient-targeted intervention methods

Method	Description	Example
<i>Checklist</i>	A list of frequently asked questions; provides patients with the opportunity to make note of questions they wish to ask during the consultation	Butow et al (1994) provided patients with a worksheet consisting of example questions and space for patients to write five questions they wished to ask
<i>Coaching</i>	One-to-one interaction between a research assistant and patient stressing the importance of patient participation; frequently includes role-playing	In a study by McGee et al (1998), a health educator met with each patient to discuss patient's goals for the consultation, encourage patients to ask questions, and assist with wording and writing of questions
<i>Educational Materials</i>	Written materials provided to patients addressing the importance of communication in the consultation and encouraging patients to clarify the questions they have and the reasons for their visit	Frederikson et al (1995) included in their intervention a leaflet encouraging patients to think about the reasons for their visit, the concerns they have, and what they'd like their provider to do
<i>Goal-Setting</i>	Patients identify the goals they would like to reach with regards to self-management or lifestyle change	In a study by Gagne and colleagues (2003), patients were provided with a notebook in which to record self-defined goals and progress toward them; providers regularly engaged patients in discussion about their goals
Patient <i>Group Education</i>	Education provided to groups of patients, generally focusing on increasing patient participation in the health-care consultation	Dow et al (1991) presented the Medical Communication Skills Program ('MedCom') to patients, with an emphasis on asking medication-related questions and providing information
<i>Patient-held Record</i>	Patients have access to their medical records and are able to contribute to the information contained in them	Williams et al (2001) provided patients with a booklet containing their past medical records plus space for entries by patients and professionals; patients were encouraged to write questions and comments in their record
<i>Patient-reported Outcome Measures</i>	Patients are asked to fill out questionnaires that elicit information about health status or quality of life issues; patient responses are then fed back to providers	Velikova et al (2004) reported patient responses to the EORTC QLQ-C30 to the patients' providers, giving providers additional information on patient quality of life
<i>Questionnaires (other)</i>	Patients are asked to fill out questionnaires that don't fall into the traditional category of PROMs. Patient responses are fed back to their providers	Feuerstein et al (1989) asked patients to fill out the Weight Loss Profile, which identifies problem areas in weight loss. Providers were then apprised of patient problem areas
<i>Values Clarification</i>	Patients work through an exercise that helps them to identify their priorities and preferences regarding a medical decision	O'Connor et al (1999) provided menopausal patients with a decision aid for hormone replacement therapy (HRT). As part of the decision aid, patients were asked to rate each benefit and risk of HRT in terms of its importance to them

Table 5b Descriptions and examples of provider-targeted intervention methods

	Method	Description	Example
Provider	<i>Provider Educational Materials</i>	Written information on problems in health care communication and/or ways to improve communication	Evans et al (1987) gave clinicians materials describing techniques to address common communication problems
	<i>Provider Prompt list</i>	List of items designed to prompt the provider to take certain actions during the consultation	McLean et al (2004) used a prompt sheet of example questions to encourage providers to ask questions eliciting patient concerns
	<i>Provider Training</i>	Communication skills training for providers emphasising eliciting patient information about problems, priorities for the visit, and/or preferences for treatment or management	Pill et al (1998) trained providers in communication skills meant to allow patients to air their concerns, select discussion topics, and set targets for themselves

The feedback to providers of patient-reported outcome measures was the most commonly employed intervention, followed by provider communication skills training. Table 6 shows each intervention method as a proportion of all reported methods.

Table 6 Frequency of use of intervention methods

	Intervention Method	N	%
Patient	<i>Checklist of frequently asked questions</i>	13	7
	<i>Coaching in communication skills</i>	16	9
	<i>Educational materials on communication</i>	16	9
	<i>Goal setting for self-management</i>	9	5
	<i>Group education on health-care communication</i>	3	2
	<i>Patient-held medical record</i>	8	5
	<i>Patient-reported outcome measures (PROMs) plus feedback of results to providers</i>	39	22
	<i>Questionnaires other than PROMs plus feedback of results to providers</i>	16	9
	<i>Values clarification exercise to identify preferences for treatment or management</i>	10	6
	<i>Other patient intervention*</i>	10	6
Provider	<i>Provider educational materials on communication</i>	2	1
	<i>Provider prompt list to encourage providers to elicit patient problems, priorities, and preferences</i>	6	3
	<i>Provider training in communication skills</i>	27	15
	<i>Other provider intervention[‡]</i>	2	1
	Total	176[†]	100

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† Because each study could have multiple intervention arms, and each intervention arm could include multiple intervention methods, there were more intervention methods reported (176) than intervention arms (146) and more intervention arms than studies (137)

The method of delivery of the majority of provider-targeted interventions was a continuing education-type class. Of the patient-targeted interventions, 57% were in a written format, 32% were face-to-face, 9% were computerized, and 2% were presented on video. Accounting for the 25% of patient interventions that were not delivered in-clinic, 9% were mailed, 6% were taken home by the patient, 2% were community-based, 2% were delivered by telephone, 2% were delivered by an unspecified method, and 4% were delivered by other means.

The timing of delivery ranged from 4 weeks pre-consultation to immediately pre-consultation (i.e. the intervention was delivered in the waiting room). Forty-six percent of interventions were delivered immediately prior to consultation, 3% were delivered 2-3 days prior, 5% 1-4 weeks prior, 4% at another time, and for 43% of interventions the timing was not specified.

d) Outcome measures

The wide range of reported study outcomes was classified as follows:

- Patient adherence
- Patient anxiety
- Patient behaviour change
- Patient decisional conflict
- Patient health status
- Patient involvement in decision-making
- Patient quality of life
- Patient recall
- Patient resource use
- Patient satisfaction
- Patient self-efficacy
- Patient-provider communication
- Patient-provider concordance/agreement
- Provider recognition of patient problems
- Provider management of patient conditions
- Provider satisfaction
- Visit length
- Other

For the purposes of analysis, these results were grouped into 7 broad outcome domains (shown in table 7). The frequency with which each outcome domain is measured can be seen in table 8. The most commonly measured outcome domains are satisfaction, health status, and communication.

Table 7 Study outcomes included in each outcome domain

Outcome Domain	Results Included
<i>Communication</i>	<ul style="list-style-type: none"> • Patient-provider communication
<i>Decision Satisfaction</i>	<ul style="list-style-type: none"> • Patient involvement in decision-making • Patient-provider concordance • Patient decisional conflict
<i>Patient Attitudes & Behaviours</i>	<ul style="list-style-type: none"> • Patient self-efficacy • Patient adherence • Patient behaviour change
<i>Provider Attitude & Behaviours</i>	<ul style="list-style-type: none"> • Provider recognition of patient problems • Provider management of patient conditions
<i>Satisfaction</i>	<ul style="list-style-type: none"> • Patient satisfaction
<i>Health Status</i>	<ul style="list-style-type: none"> • Patient health status • Patient quality of life
<i>Resource Use</i>	<ul style="list-style-type: none"> • Patient resource use • Visit length

Table 8 Frequency of domain measurement

Outcome Domain	N	%
<i>Communication</i>	61	20
<i>Decision Satisfaction</i>	22	7
<i>Patient Attitudes & Behaviours</i>	33	11
<i>Provider Attitudes & Behaviours</i>	44	14
<i>Satisfaction</i>	66	21
<i>Health Status</i>	63	20
<i>Resource Use</i>	20	7
<i>Total</i>	309 [†]	100.0

[†] Because most studies reported multiple outcomes, there were more outcomes reported (309) than studies (137).

The domains in tables 7 and 8 are ordered by ‘quasi-temporality’, or their position on a theoretical causal pathway between an intervention and a measured outcome. Informed by the work of Bodenheimer et al (2002), Greenhalgh et al (2005), and Heisler et al (2003), figure 2 presents a possible causal pathway by which collaborative care may have an impact on patient and provider outcomes. Grouping results by ‘quasi-temporality’, or where on this pathway each result occurs, allows analysis of how an intervention might affect patient and provider outcomes. For example, effects of an intervention on both communication and decision satisfaction, without improvement in health outcomes, suggests that the intervention may have failed to impact patient and/or provider attitudes or behaviours.

As can be seen from table 9, outcome domains measured in the studies are strongly related to the method of intervention employed by that study, so that within each category of intervention method, some domains have been intensively studied while others have been largely ignored. Thus, 40% of the measured outcomes in studies using checklists as an intervention were related to communication, while just 6% of the measured outcomes of patient-reported outcome measures were communication-related.

Figure 2 Proposed pathway between collaborative care and patient and provider outcomes

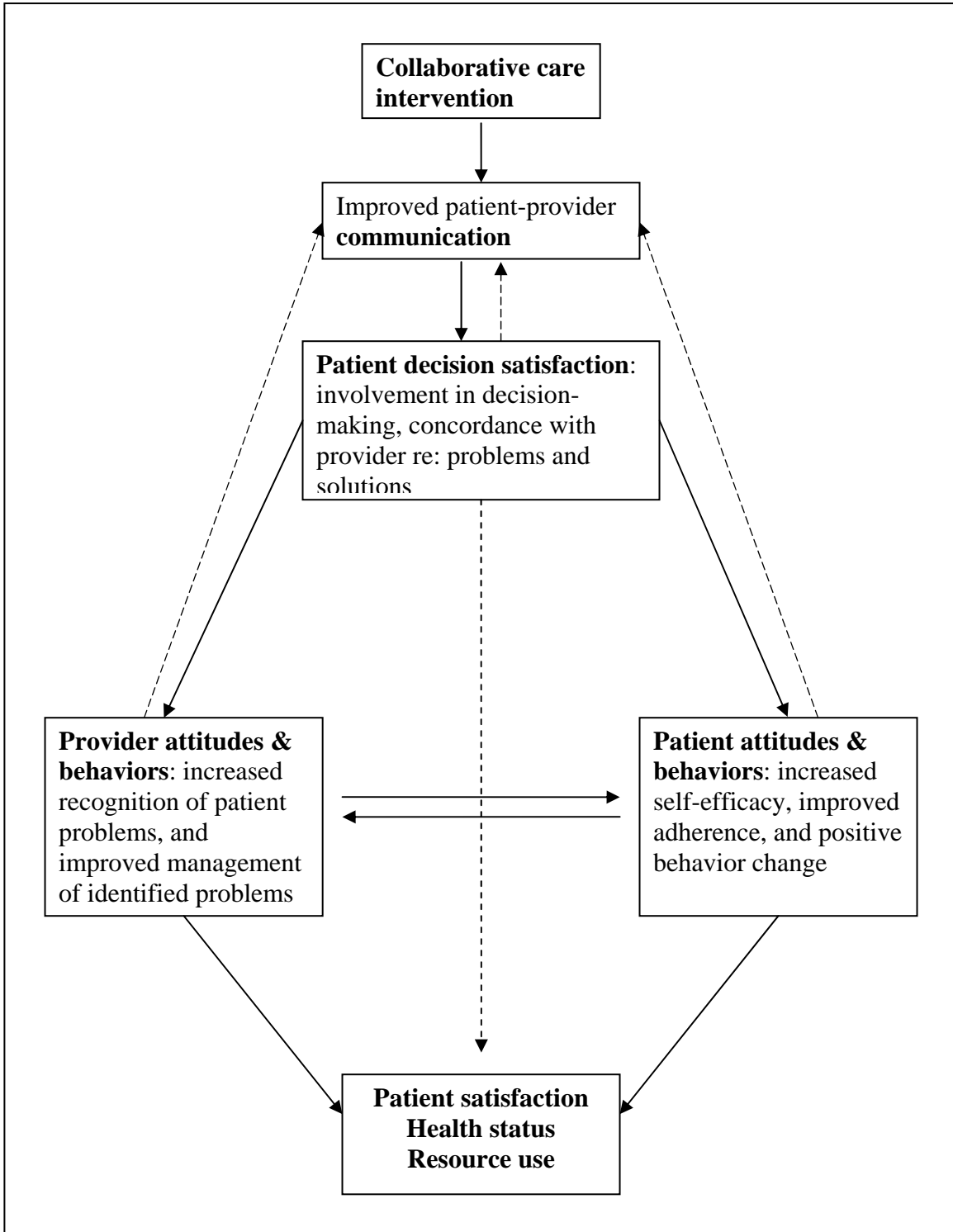


Table 9a Frequency of outcome domain measurement by patient-targeted intervention method

	Outcome Domain													
	Communication		Decision Satisfaction		Patient Attitudes & Behaviours		Provider Attitudes & Behaviours		Satisfaction		Health Status		Resource Use	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
<i>Checklist of frequently asked questions</i>	12	40	1	3	2	7	2	7	10	33	1	3	2	7
<i>Coaching in communication skills</i>	12	28	5	12	6	14	—	—	7	16	11	26	2	5
<i>Educational materials on communication</i>	16	36	2	5	6	14	—	—	9	21	8	18	3	7
<i>Goal setting for self-management</i>	—	—	—	—	6	40	—	—	2	13	7	47	—	—
<i>Group education on health-care communication</i>	2	33	1	17	2	33	—	—	1	17	—	—	—	—
<i>Patient-held medical record</i>	—	—	—	—	4	27	—	—	5	33	3	27	2	13
<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	5	6	1	1	1	1	33	40	13	16	22	27	7	9
<i>Questionnaires other than PROMs + feedback of results</i>	4	12	2	6	5	15	5	15	10	29	8	24	—	—
<i>Values clarification exercise to identify patient preferences</i>	—	—	10	53	2	11	—	—	4	21	2	11	1	5
<i>Other patient intervention*</i>	5	25	2	10	1	5	—	—	2	10	9	45	1	5

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

Table 9b Frequency of outcome domain measurement by provider-targeted intervention method

Intervention Method	Outcome Domain													
	Commun-ication		Decision Satisfaction		Patient Attitudes & Behaviours		Provider Attitudes & Behaviours		Satisfaction		Health Status		Resource Use	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
<i>Provider educational materials on communication</i>	—		—		—		1	33	2	67	—		—	
Provider <i>Provider prompt list to encourage providers to elicit patient information</i>	—		—		1	20	—		1	20	2	40	1	20
<i>Provider training in communication skills</i>	25	31	1	1	14	17	11	13	18	22	9	11	4	5
<i>Other provider intervention</i> [‡]	4	29	—		1	7	2	14	3	21	4	29	—	

[‡] 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

e) Study results

The impact of the interventions on outcomes varies widely across outcome domains. Overall, communication is most positively affected by the interventions, followed by provider attitudes/behaviours and decision satisfaction. These results are presented in table 10. Table 10 shows the results by 'quasi-temporality' (where the domain falls on the causal pathway in figure 2) and by study temporality, or when the results were measured in relation to the intervention. Study temporality is designated by the terms 'short-term', 'intermediate', and 'long-term'. For the purposes of this review, 'short-term' applies to results measured immediately after the intervention up to one week post-intervention, 'intermediate' means two to 8 weeks post-intervention, and 'long-term' refers to those results measured 3 months or more after the intervention was completed.

As table 10 shows, most domains are measured in the short term, with the exceptions of patient attitudes/behaviours and health status, which are most often studied as long-term results. It is also possible to see from table 10 that there is a trend for domains that come earlier on the causal pathway (e.g. communication) to be more positively affected by the interventions.

Table 11 shows intervention effects over the short, intermediate, and long terms broken down by whether the intervention was targeted at the patient or provider. Overall, the short-term outcomes presented in table 11 appear to be comparable between patient- and provider-targeted interventions. Table 12, which presents combined outcomes for patient-versus provider-targeted interventions, supports this appearance. In the intermediate and long term, the numbers are too small to detect whether the intervention effectiveness differs depending on its target.

When all outcomes are combined, one-to-one coaching, PROMs, and values clarification appear to be the most successful, at least in the short-term. Table 13 presents combined outcomes for each intervention method.

Tables 14a through 14g present the short-, intermediate, and long-term effects of each type of intervention method on the seven outcome domains.

Table 10 Study results for all interventions combined

Outcome Domain	Results								
	Short-Term*			Intermediate*			Long-Term*		
	N	+ [†]	%	N	+	%	N	+	%
<i>Communication</i>	53	35	66	6	3	50	2	2	100
<i>Decision Satisfaction</i>	17	9	53	2	2	100	4	0	0
<i>Provider Attitudes & Behaviours</i>	31	18	58	4	1	25	6	4	67
<i>Patient Attitudes & Behaviours</i>	10	3	30	10	2	20	17	2	12
<i>Satisfaction</i>	44	9	21	11	2	18	13	2	15
<i>Health Status</i>	11	2	18	18	6	33	31	9	28
<i>Resource Use</i>	10	3	30	0	—	—	7	2	29

*For the purposes of this review, 'short-term' applies to results measured immediately after the intervention up to one week post-intervention, 'intermediate' means two to 8 weeks post-intervention, and 'long-term' refers to those results measured 3 months or more after the intervention was completed

†For definition of 'positive' (+) see table 4 footnote

Table 11 Study results for patient- and provider-targeted interventions

Outcome Domain	Intervention Target	Results								
		Short-Term*			Intermediate*			Long-Term*		
		N	+ [†]	%	N	+	%	N	+	%
<i>Communication</i>	Patient	53	35	66	3	1	33	1	1	100
	Provider	25	17	68	3	2	67	3	1	33
<i>Decision Satisfaction</i>	Patient	22	11	50	2	2	100	4	0	0
	Provider	1	1	100	0	—	—	0	—	—
<i>Patient Attitudes & Behaviours</i>	Patient	8	5	63	7	3	43	21	1	5
	Provider	8	1	13	10	1	10	6	1	17
<i>Provider Attitudes & Behaviours</i>	Patient	28	16	57	3	1	33	9	4	44
	Provider	13	8	62	1	0	0	1	0	0
<i>Satisfaction</i>	Patient	41	9	22	13	2	15	12	2	17
	Provider	18	6	33	3	0	0	5	1	20
<i>Health Status</i>	Patient	10	2	20	18	7	39	49	13	27
	Provider	6	0	0	5	1	20	6	1	17
<i>Resource Use</i>	Patient	9	3	33	0	—	—	9	2	22
	Provider	4	1	25	0	—	—	1	0	0

* See table 10 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

†For definition of 'positive' (+) see table 4 footnote

Table 12 All study outcomes combined by intervention target

Intervention Target	Results								
	Short-Term [†]			Intermediate [†]			Long-Term [†]		
	N	+ [‡]	%	N	+	%	N	+	%
<i>Patient</i>	209 [*]	95	45	70	19	27	118	24	20
<i>Provider</i>	86 [*]	39	45	37	6	16	31	7	23

[†]For the purposes of this review, 'short-term' applies to results measured immediately after the intervention up to one week post-intervention, 'intermediate' means two to 8 weeks post-intervention, and 'long-term' refers to those results measured 3 months or more after the intervention was completed

^{*}Because most studies reported multiple outcomes, there are more outcomes reported here (295) than studies (137).

[‡]For definition of 'positive' (+) see table 4 footnote

Table 13 All study outcomes combined by intervention

Intervention Method	Results								
	Short-Term [†]			Intermediate [†]			Long-Term [†]		
	N	+ ^{**}	%	N	+	%	N	+	%
<i>Checklist of frequently asked questions</i>	28	13	46	19	1	5	0	—	—
<i>Coaching in communication skills</i>	32	17	53	10	4	40	11	2	18
<i>Educational materials on communication</i>	45	19	42	5	2	40	10	3	30
<i>Goal setting for self-management</i>	0	—	—	9	4	44	11	2	18
<i>Group education on health-care communication</i>	5	2	40	0	—	—	1	0	0
<i>Patient-held medical record</i>	3	0	0	0	—	—	12	0	0
<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	36	18	50	17	6	35	42	10	24
<i>Questionnaires other than PROMs + feedback of results</i>	32	12	38	4	1	25	9	3	33
<i>Values clarification exercise to identify patient preferences</i>	16	8	50	3	1	33	12	1	8
<i>Other patient intervention*</i>	13	6	46	3	0	0	10	3	30
<i>Provider educational materials on communication</i>	5	5	100	0	—	—	0	—	—
<i>Provider prompt list to encourage providers to elicit patient info</i>	9	2	22	1	0	0	0	—	—
<i>Provider training in communication skills</i>	67	30	45	32	6	19	31	7	23
<i>Other provider intervention[‡]</i>	5	2	40	4	0	0	0	—	—

^{*}'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

[‡]'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

[†] See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term' ^{**} For definition of 'positive' (+) see table 4 footnote

Table 14a The effects of patient and provider interventions on *communication*

	Intervention Method	Results								
		Short-Term [†]			Intermediate [†]			Long-Term [†]		
		N	+ ^{**}	%	N	+	%	N	+	%
Patient	<i>Checklist of frequently asked questions</i>	11	5	45	1	0	0	0	—	—
	<i>Coaching in communication skills</i>	12	10	83	0	—	—	0	—	—
	<i>Educational materials on communication</i>	16	11	69	0	—	—	0	—	—
	<i>Goal setting for self-management</i>	0	—	—	0	—	—	0	—	—
	<i>Group education on health-care communication</i>	2	2	100	0	—	—	0	—	—
	<i>Patient-held medical record</i>	0	—	—	0	—	—	0	—	—
	<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	3	2	67	1	1	100	1	1	100
	<i>Questionnaires other than PROMs + feedback of results</i>	4	1	25	1	0	0	0	—	—
	<i>Values clarification exercise to identify patient preferences</i>	0	—	—	0	—	—	0	—	—
	<i>Other patient intervention*</i>	5	4	80	0	—	—	0	—	—
Provider	<i>Provider educational materials on communication</i>	0	—	—	0	—	—	0	—	—
	<i>Provider prompt list to encourage providers to elicit patient info</i>	0	—	—	0	—	—	0	—	—
	<i>Provider training in communication skills</i>	21	15	71	3	2	67	3	1	33
	<i>Other provider intervention[‡]</i>	4	2	50	0	—	—	0	—	—

*‘Other patient intervention’ includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and ‘collaborative therapy’ focusing on identifying patient problems and priorities (1)

‡ ‘Other provider intervention’ includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of ‘short-term’, ‘intermediate’, and ‘long-term’

** For definition of ‘positive’ (+) see table 4 footnote

Table 14b The effects of patient and provider interventions on *decision satisfaction*

	Results								
	Short-Term[†]			Intermediate[†]			Long-Term[†]		
	N	+^{**}	%	N	+	%	N	+	%
Intervention Methods									
Patient									
<i>Checklist of frequently asked questions</i>	1	0	0	0	—	0	—	—	—
<i>Coaching in communication skills</i>	4	1	25	1	1	100	0	—	—
<i>Educational materials on communication</i>	2	0	0	0	—	0	—	—	—
<i>Goal setting for self-management</i>	0	—	—	—	—	0	—	—	—
<i>Group education on health-care communication</i>	1	0	0	0	—	0	—	—	—
<i>Patient-held medical record</i>	0	—	—	0	—	0	—	—	—
<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	1	0	0	0	—	0	—	—	—
<i>Questionnaires other than PROMs + feedback of results</i>	3	2	67	0	—	0	—	—	—
<i>Values clarification exercise to identify patient preferences</i>	8	6	75	1	1	100	4	0	0
<i>Other patient intervention*</i>	2	2	100	0	—	0	—	—	—
Provider									
<i>Provider educational materials on communication</i>	0	—	—	0	—	0	—	—	—
<i>Provider prompt list to encourage providers to elicit patient info</i>	1	1	100	0	—	0	—	—	—
<i>Provider training in communication skills</i>	0	—	—	0	—	0	—	—	—
<i>Other provider intervention[‡]</i>	0	—	—	0	—	0	—	—	—

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

** For definition of 'positive' (+) see table 4 footnote

Table 14c The effects of patient and provider interventions on *patient attitudes and behaviours*

Intervention Methods		Results								
		Short-Term [†]			Intermediate [†]			Long-Term [†]		
		N	+	%	N	+	%	N	+	%
Patient	<i>Checklist of frequently asked questions</i>	2	1	50	0	—	0	—	0	—
	<i>Coaching in communication skills</i>	2	2	100	1	0	0	3	0	0
	<i>Educational materials on communication</i>	2	2	100	3	2	67	1	0	0
	<i>Goal setting for self-management</i>	0	—	—	1	1	100	5	0	0
	<i>Group education on health-care communication</i>	1	0	0	0	—	—	1	0	0
	<i>Patient-held medical record</i>	0	—	—	0	—	—	4	0	0
	<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	0	—	—	0	—	—	1	0	0
	<i>Questionnaires other than PROMs + feedback of results</i>	0	—	—	1	0	0	4	0	0
	<i>Values clarification exercise to identify patient preferences</i>	1	0	0	1	0	0	1	0	0
	<i>Other patient intervention*</i>	0	—	—	0	—	—	1	1	100
Provider	<i>Provider educational materials on communication</i>	0	—	—	0	—	—	0	0	0
	<i>Provider prompt list to encourage providers to elicit patient info</i>	1	0	0	0	—	—	0	—	—
	<i>Provider training in communication skills</i>	7	1	14	10	1	10	6	1	17
	<i>Other provider intervention[‡]</i>	0	—	—	0	—	—	0	—	—

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

** For definition of 'positive' (+) see table 4 footnote

Table 14d The effects of patient and provider interventions on *provider attitudes and behaviours*

Intervention Methods		Results								
		Short-Term [†]			Intermediate [†]			Long-Term [†]		
		N	+ ^{**}	%	N	+	%	N	+	%
Patient	<i>Checklist of frequently asked questions</i>	2	2	100	0	—	0	—	0	—
	<i>Coaching in communication skills</i>	0	—	—	0	—	0	—	0	—
	<i>Educational materials on communication</i>	0	—	—	0	—	0	—	0	—
	<i>Goal setting for self-management</i>	0	—	—	0	—	0	—	0	—
	<i>Group education on health-care communication</i>	0	—	—	0	—	0	—	0	—
	<i>Patient-held medical record</i>	0	—	—	0	—	0	—	0	—
	<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	21	11	52	3	1	33	9	4	44
	<i>Questionnaires other than PROMs + feedback of results</i>	5	3	60	0	—	—	0	—	—
	<i>Values clarification exercise to identify patient preferences</i>	0	—	—	0	—	—	0	—	—
	<i>Other patient intervention*</i>	0	—	—	0	—	—	0	—	—
Provider	<i>Provider educational materials on communication</i>	1	1	100	1	0	0	0	—	—
	<i>Provider prompt list to encourage providers to elicit patient info</i>	2	1	50	0	—	—	0	—	—
	<i>Provider training in communication skills</i>	10	6	60	0	—	—	1	0	0
	<i>Other provider intervention[‡]</i>	0	—	—	0	—	—	0	—	—

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

** For definition of 'positive' (+) see table 4 footnote

Table 14e The effects of patient and provider interventions on patient-reported *satisfaction*

Intervention Methods		Results								
		Short-Term[†]			Intermediate[†]			Long-Term[†]		
		N	+^{**}	%	N	+	%	N	+	%
Patient	<i>Checklist of frequently asked questions</i>	4	3	75	6	1	17	0	—	
	<i>Coaching in communication skills</i>	6	0	0	1	0	0	0	—	
	<i>Educational materials on communication</i>	7	1	14	0	—		2	1	50
	<i>Goal setting for self-management</i>	0	—		2	0	0	0	—	
	<i>Group education on health-care communication</i>	1	0	0	0	—		0	—	
	<i>Patient-held medical record</i>	1	0	0	0	—		4	0	0
	<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	8	3	38	3	0	0	3	1	33
	<i>Questionnaires other than PROMs + feedback of results</i>	10	2	20	1	1	100	0	—	
	<i>Values clarification exercise to identify patient preferences</i>	3	0	0	0	—		2	0	0
	<i>Other patient intervention*</i>	1	0	0	0	—		1	0	0
Provider	<i>Provider educational materials on communication</i>	2	2	100	0	—		0	—	
	<i>Provider prompt list to encourage providers to elicit patient info</i>	1	0	0	0	—		0	—	
	<i>Provider training in communication skills</i>	14	4	29	1	0	0	5	1	20
	<i>Other provider intervention[‡]</i>	1	0	0	2	0	0	0	—	

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

** For definition of 'positive' (+) see table 4 footnote

Table 14f The effects of patient and provider interventions on *health status*

	Results								
	Short-Term [†]			Intermediate [†]			Long-Term [†]		
	N	+	%	N	+	%	N	+	%
Intervention Methods									
<i>Checklist of frequently asked questions</i>	1	1	100	0	—	—	0	—	—
<i>Coaching in communication skills</i>	1	1	100	3	1	33	7	2	29
<i>Educational materials on communication</i>	0	—	—	2	0	0	6	2	33
<i>Goal setting for self-management</i>	0	—	—	3	2	67	4	1	25
<i>Group education on health-care communication</i>	0	—	—	0	—	—	0	—	—
<i>Patient-held medical record</i>	2	0	0	0	—	—	2	0	0
<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	1	0	0	8	4	50	18	3	17
<i>Questionnaires other than PROMs + feedback of results</i>	3	0	0	1	0	0	4	3	75
<i>Values clarification exercise to identify patient preferences</i>	0	—	—	0	—	—	2	0	0
<i>Other patient intervention*</i>	2	0	0	1	0	0	6	2	33
Provider									
<i>Provider educational materials on communication</i>	0	—	—	0	—	—	0	—	—
<i>Provider prompt list to encourage providers to elicit patient info</i>	0	—	—	0	—	—	0	—	—
<i>Provider training in communication skills</i>	3	0	0	4	0	0	6	1	17
<i>Other provider intervention[‡]</i>	3	0	0	1	1	100	0	—	—

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

** For definition of 'positive' (+) see table 4 footnote

Table 14g The effects of patient and provider interventions on *resource use*

Intervention Methods		Results								
		Short-Term [†]			Intermediate [†]			Long-Term [†]		
		N	+	%	N	+	%	N	+	%
Patient	<i>Checklist of frequently asked questions</i>	2	0	0	0	—	0	—	0	—
	<i>Coaching in communication skills</i>	2	1	50	0	—	0	—	0	—
	<i>Educational materials on communication</i>	3	2	67	0	—	0	—	0	—
	<i>Goal setting for self-management</i>	0	—	—	0	—	0	—	0	—
	<i>Group education on health-care communication</i>	0	—	—	0	—	0	—	0	—
	<i>Patient-held medical record</i>	0	—	—	0	—	1	0	0	—
	<i>Patient-reported outcome measures (PROMs) + feedback of results</i>	0	—	—	0	—	7	1	14	—
	<i>Questionnaires other than PROMs + feedback of results</i>	1	0	0	0	—	0	—	0	—
	<i>Values clarification exercise to identify patient preferences</i>	0	—	—	0	—	1	1	100	—
	<i>Other patient intervention*</i>	1	0	0	0	—	0	—	0	—
Provider	<i>Provider educational materials on communication</i>	0	—	—	0	—	0	—	0	—
	<i>Provider prompt list to encourage providers to elicit patient info</i>	1	1	100	0	—	0	—	0	—
	<i>Provider training in communication skills</i>	3	0	0	0	—	1	0	0	—
	<i>Other provider intervention[‡]</i>	0	—	—	0	—	0	—	0	—

*'Other patient intervention' includes telephone calls (2 studies), video of actor modelling desired patient behaviour (2), audiotape of consultation given to the patient (2), facilitation of the consultation by the researcher (1), and 'collaborative therapy' focusing on identifying patient problems and priorities (1)

‡ 'Other provider intervention' includes individual feedback from mentor regarding communication skills (1 study) and notification of patient allocation to experimental or control groups (1)

† See table 12 footnote for definitions of 'short-term', 'intermediate', and 'long-term'

** For definition of 'positive' (+) see table 4 footnote

Chapter 4: DISCUSSION

This review identified diverse strategies, mostly targeted toward the patient, for increasing patient-provider collaboration in health care. This range of collaborative strategies was paralleled by an equally diverse array of measured outcomes. For the purpose of the review, these outcomes were grouped into seven broad outcome domains to enable comparison across studies. Patient satisfaction, health status, and patient-provider communication were the most commonly assessed outcome domains, with communication showing a highly positive response to interventions. This positive effect was seen in studies employing both patient- and provider-targeted interventions.

Similarly, the effect of the interventions on patient decision satisfaction and provider behaviour (e.g. diagnosis and management of patient conditions) outcome domains was largely positive. In contrast, patient behaviours, satisfaction, health status, and resource use were positively affected in 30% or fewer of cases. Positive results were more often seen in the short term and were, in general, diminished in the intermediate and long term. Thus, the interventions presented in this review appear to have the greatest impact shortly after intervention delivery and on proximal outcomes (those that come early in the causal pathway presented in figure 2). Because of the small number of studies that include long-term measures, however, it is not possible to determine whether this trend represents a true reduction in intervention effectiveness over time. Furthermore, few studies included outcomes representative of all the broad domains described in this ‘quasi-temporal’ pathway, particularly the more distal outcomes (i.e. those that come later in the causal pathway), making it impossible to trace the effect of a given intervention strategy along the causal pathway. For instance, while the impact of provider training on communication outcomes has been well-measured, the impact on health status has rarely been assessed, making it impossible to determine whether improved communication due to provider training has an impact on patient health.

Within the included studies, the most commonly employed intervention strategy was feedback to providers of patient-reported outcome measures. The vast majority of these PROMs studies reported provider behaviours as the primary outcome, with the expectation that PROMs would serve as screening tools to improve provider diagnosis and management behaviours. Encouragingly, these evaluations found fairly positive results. However, it might be argued that offering patients a screening questionnaire is only minimally collaborative in the sense that it increases the flow of information about problems from patient to provider but does little to help patients identify their priorities and preferences. Furthermore, while the impact of PROMs feedback on provider actions has been fairly well studied, other outcomes, such as communication, have been relatively neglected, leaving the true benefit of PROMs feedback unknown. Finally, most PROMs intervention studies evaluated the effect of a single PROMs report fed back to physicians; few studies assessed the impact of regular PROMs feedback over time or addressed the question of which provider (e.g. physician, nurse, or allied health professional) is most appropriate to receive such feedback. Exploring more collaborative uses of PROMs, establishing the best timing of delivery, and determining the most appropriate provider to receive PROMs information will allow optimisation of PROMs interventions.

There are a number of methodological difficulties that complicate the review of collaboration-based interventions. First, as was noted in the introduction, interventions that aim to change

human interactions are often complex, making it difficult to parse out the essential components. Although the review has attempted to focus on the collaborative care element of chronic disease management, it was not always clear where one element ended and where another element began. For example, the provision of patient education tailored to problems identified in a patient-reported outcome measure could be seen as a natural outgrowth of a PROMs intervention, or it could be seen as an additional component that confounds the interpretation of results. A second methodological difficulty was the poor reporting of most of the studies, which compounded the challenge of defining individual components because it made it difficult to interpret what was included in an intervention. The quality of reporting also impeded the assessment of study quality and thus made it impossible to evaluate the strength of the evidence.

Chapter 5: CONCLUSION

Key components of improved care for individuals with chronic disease crucially include increased involvement of the patient in decisions about care and greater collaboration between patient and health professional. This review has demonstrated that an extremely wide range of interventions have been tested that may enhance patient involvement and increase collaboration between patient and health-care provider, whether by influencing the behaviour of the patient, the provider or both. One of the most striking impressions of the evidence assembled is that positive and encouraging evidence is widely available that changes may be brought about in desired directions. The patient-provider relationship is far from static and the scope and potential for greater partnership is enormous.

The most and most encouraging evidence is available for shorter term changes in outcomes. Although some evidence is available to indicate that there are longer term benefits for patients from increased involvement as defined by this review, it is disappointing that so few studies consider partnership in chronic disease as a long term matter with constant need to maintain and develop partnership and collaboration and assess long term impact on outcomes for patients. Longer term studies are needed to assess the full extent of benefits to patients of developments such as the Expert Patients Programme. Studies also need to capture the evolving nature of shared decisions more effectively than does the current emphasis on the evidence of effects of single consultations or short-term care processes. Moreover, the success of different interventions in enhancing patient involvement in the health-care process may be influenced by a variety of external factors including a patient's previous encounter with the health-care system (Espallargues et al, 2000) and the ongoing nature of the disease process. That is, patients who have acknowledged the chronicity of their conditions may be more amenable to shared decision making and goal setting.

Amongst the most commonly studied of mechanisms to enhance patient involvement and partnership building is the use of patient-reported outcome measures. Contrary to some other reviews, the results of the current review provide encouraging evidence that patient-reported outcome measures may be effective in positively improving patient involvement and ultimately positively influencing some important longer-term outcomes. The availability of this promising evidence suggests that more attention needs to be given to how exactly patients and health professionals may use and benefit from structured reporting of patient health and health-related

concerns through such measures. Some of the positive evidence for benefits of patient-reported outcome measures is essentially evidence of their use by health professionals as quasi-screening instruments to high-light otherwise hidden or overlooked problems. This evidence is based on a still somewhat passive role for the patient. Work is still needed to examine whether and how patient-reported outcome measures may more broadly facilitate shared decision-making and the active patient involvement. Again, imaginative applications and longer-term studies are needed fully to explore the role of patient-reported outcome measures in the context of dynamic and evolving relations of patients and health professionals coping with chronic disease.

There is a preponderance of evidence involving doctors in the current review. In a world of multi-disciplinary care and substitution of medical inputs wherever appropriate, it would be timely for studies to test methods of enhancing patient involvement in decisions shared with other health-care providers.

Overall, the scope and potential for increased patient involvement and greater sharing of decisions is substantial and the evidence is encouraging that such changes are beneficial. Evidence such as is provided by the current review should encourage the NHS to consider seriously, and adapt from a variety of possible routes, strategies to achieve increased partnership and collaborative care in addressing chronic disease.

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Appendix I: Search terms for secondary searches

1. Patient-reported outcome measures (columns joined by 'and'):

PATIENT-REPORTED OUTCOME MEASURES (joined by 'OR')	OUTCOME (joined by 'OR')
<ul style="list-style-type: none"> • (health status or functional status or functional assessment or self report* or self rat* or self administer*) near2 (measure* or instrument* or questionnaire*) • zung self rat* depression scale* • general health questionnaire 	<ul style="list-style-type: none"> • (change* or improve* or increase* or effect*) near (recogni* or treatment* or detect* or (patient* adj outcome*) or diagnos* or awareness) • ((patient* or client*) near (provider* or physician* or clinician* or doctor*)) near (agree* or relationship or communication) • patient satisfaction

2. Individualized Measures:

(joined by 'OR')

- | | |
|---|---|
| <ul style="list-style-type: none"> • Patient generated index • Client generated index • Mother generated index • Patient specific index • Individually prioritized problem assessment • Goal attainment scaling • Personal functional goals interview protocol • Personal impact health assessment questionnaire • MYMOP • Repertory grid structured interview technique • Subjective quality of life profile OR (SQLP) • Life fulfillment scale • SEIQOL • Satisfaction with life scale OR SWLS • Individual quality of life interview OR IQOLI • Quality of life systemic inventory OR QLSI | <ul style="list-style-type: none"> • Flanagan quality of life scale OR QOLS • SBQOL • Quality of life assessment schedule • GRIDQOL • Individualized multidimensional quality of life model • WHOQOL • Ferrans and Powers quality of life index • Wisconsin quality of life index • Quality of life GAP • MACTAR • Frenchay activities index • Canadian occupational performance measure • Renal-dependent individualized quality of life questionnaire • University of Washington head and neck questionnaire • Asthma quality of life questionnaire • Chronic respiratory questionnaire |
|---|---|

3. Pain Assessment (columns joined by ‘and’):

Pain Assessment (joined by ‘OR’)	Routine (joined by ‘OR’)	Exclusions
<ul style="list-style-type: none"> • Pain assess* 	<ul style="list-style-type: none"> • Systemat* • Routine • Record* 	<ul style="list-style-type: none"> • ‘patient controlled analgesia’ • child* • pediatric* • ‘end of life’ • palliative • hospice

4. Patient-held Records:

(joined by ‘OR’)

- Patient held record*
- Patient* hold* record*

5. Self-management (columns joined by ‘and’):

SELF-MANAGEMENT (joined by ‘OR’)	PURPOSE (joined by ‘OR’)	OUTCOME (joined by ‘OR’)
<ul style="list-style-type: none"> • Self manag* • Self care 	<ul style="list-style-type: none"> • Communication and patient* • Consultation and patient* and participat* • Patient* concern* • Question* ask* • Action plan* • Goal set* • Individual* goal* • Share* decision making • Patient involv* • Patient participat* • Self manag* • ((Patient* or client*) near2 (clinician* or professional* or provider* or physician* or doctor* or nurse*)) near (communicat* or collaborat* or negotiat* or consult* or discuss* or dialog*) 	<ul style="list-style-type: none"> • Explode ‘outcome-and – process-assessment-health-care’/all subheadings • (Evaluat* or effect*) and (intervention*) • (Patient or provider) and satisfaction • Self efficacy • Adherence • Compliance • Concordance • Health status • Quality of life

Appendix II: Data extraction form

I. PUBLICATION DETAILS

- A. Author(s): _____

- B. Title: _____

- C. Journal/Source: _____
Year: _____ Volume: _____ Issue: _____ Pages: _____
- D. Country of Origin: i. US ii. UK iii. Other: _____

II. STUDY DESIGN

- A. Study type (*circle one*):
i. RCT
ii. Other: _____
- B. Study setting (*circle one*):
i. Community
ii. Primary care
iii. Specialist care:
a. outpatient
b. inpatient
c. mixed
d. not specified
iv. Other: _____
- C. Allocation of intervention/control groups (*circle one*):
i. Randomized
a. Randomization method adequate?
1. Yes
2. No/Not reported
b. Unit of randomization:
1. Patients
2. Providers
3. Practices
c. Allocation adequately concealed?
1. Yes
2. No/Not reported
ii. Other/Not reported: _____
- D. Blinding
i. Patients blinded to intervention status? (*circle one*):
a. Yes
b. No/Not reported
ii. Providers blinded to intervention status? (*circle one*):
a. Yes
b. No/Not reported
iii. Blinding of others involved in intervention implementation? (*circle one*):
a. Yes
b. No/Not reported
c. Not Applicable
- E. Additional information on study design: _____

III. SAMPLE INFORMATION

Patients	Providers																
<p>A. Sample type (<i>circle one</i>)</p> <p>i. Representative sample</p> <p>ii. Convenience/Other sample/Not reported</p> <p>iii. Not reported</p>	<p>A. Sample type (<i>circle one</i>)</p> <p>i. Representative sample</p> <p>ii. Convenience/Other sample/Not reported</p> <p>iii. Not reported</p>																
<p>B. Sample size (<i>fill in categories as they are reported</i>):</p> <p>Total:</p> <p>i. Invited: _____</p> <p>ii. Consented: _____ (_____%)</p> <p>iii. Completed: _____ (_____%)</p> <p>iv. Additional information: _____</p> <table style="display: inline-table; vertical-align: middle; margin-left: 20px;"> <tr> <td style="padding-right: 10px;">Exp:</td> <td style="padding-right: 10px;">Control:</td> </tr> <tr> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> </tr> <tr> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> </tr> <tr> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> </tr> </table>	Exp:	Control:	_____	_____	_____	_____	_____	_____	<p>B. Sample size (<i>fill in categories as they are reported</i>):</p> <p>Total:</p> <p>i. Invited: _____</p> <p>ii. Consented: _____ (_____%)</p> <p>iii. Completed: _____ (_____%)</p> <p>iv. Additional information: _____</p> <table style="display: inline-table; vertical-align: middle; margin-left: 20px;"> <tr> <td style="padding-right: 10px;">Exp:</td> <td style="padding-right: 10px;">Control:</td> </tr> <tr> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> </tr> <tr> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> </tr> <tr> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> <td style="border-left: 1px solid black; border-right: 1px solid black; height: 20px;">_____</td> </tr> </table>	Exp:	Control:	_____	_____	_____	_____	_____	_____
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<p>C. Significant differences between completers and non-completers?</p> <p>i. Yes/Not reported</p> <p>ii. No</p>	<p>C. Significant difference between completers and non-completers?</p> <p>i. Yes/Not reported</p> <p>ii. No</p>																
<p>D. Inclusion criteria:</p> <p>i. Category (e.g., neurological, cardiac, respiratory, musculoskeletal, cancer, diabetes, mental health, primary care population, age group, other): _____</p> <p>ii. Disease duration (e.g., newly diagnosed, established diagnosis, mixed, not reported/not applicable): _____</p> <p>iii. Patient relationship to clinic/provider (e.g., known/old patients, new patients, mixed, not reported): _____</p> <p>iv. Other: _____</p>	<p>D. Inclusion criteria:</p>																
<p>E. Exclusion criteria:</p>	<p>E. Exclusion criteria:</p>																
<p>F. Participant characteristics</p> <p>i. % Female: _____</p> <p>ii. Age (mean): _____</p> <p>iii. SES/Education: _____</p> <p>iv. Other: _____</p>	<p>F. Participant characteristics</p> <p>i. % Female: _____</p> <p>ii. Age (mean): _____</p> <p>iii. Level of training/ time in practice: _____</p> <p>iv. Other: _____</p>																
<p>G. Control and intervention groups significantly different at baseline?</p> <p>i. Yes/Not reported</p> <p>ii. No</p>	<p>G. Control and intervention groups significantly different at baseline?</p> <p>i. Yes/Not reported</p> <p>ii. No</p>																

IV. **DESCRIPTION OF INTERVENTION(S)** (fill out one column for each intervention in article)

- A. Study Compares (circle one/for ii. write in numbers):
 - i. One intervention to one control
 - ii. ___ (#) interventions, ___ (#) control groups
- B. Type of provider (circle all that apply):
 - i. Physician
 - ii. Nurse
 - iii. Other: _____

<p>C. Intent re: patient involvement (circle all that apply):</p> <ul style="list-style-type: none"> i. Increase patient question-asking ii. Increase patient information provision iii. Increase patient involvement in decision- making iv. Increase patient participation – general v. Improve pt.-provider communication vi. Other: _____ 	<p>C. Intent re: patient involvement (circle all that apply):</p> <ul style="list-style-type: none"> i. Increase patient question-asking ii. Increase patient information provision iii. Increase patient involvement in decision- making iv. Increase patient participation – general iii. Improve pt.-provider communication iv. Other: _____ 	<p>C. Intent re: patient involvement (circle all that apply):</p> <ul style="list-style-type: none"> i. Increase patient question-asking ii. Increase patient information provision iii. Increase patient involvement in decision- making iv. Increase patient participation – general iii. Improve pt.-provider communication iv. Other: _____
<p>D. Method of intervention (circle all that apply):</p> <ul style="list-style-type: none"> i. Patient: <ul style="list-style-type: none"> a. Patient-reported health instrument b. Other questionnaire c. Checklist d. Educational materials e. One-to-one coaching f. Group education g. Other: _____ ii. Provider: <ul style="list-style-type: none"> a. Prompt list b. Provider checklist c. Educational materials d. Communication skills training e. Training in interpretation of patient- supplied information f. Materials on interpretation of patient-supplied information g. Other: _____ 	<p>D. Method of intervention (circle all that apply):</p> <ul style="list-style-type: none"> i. Patient: <ul style="list-style-type: none"> a. Patient-reported health instrument b. Other questionnaire c. Checklist d. Educational materials e. One-to-one coaching f. Group education g. Other: _____ ii. Provider: <ul style="list-style-type: none"> a. Prompt list b. Provider checklist c. Educational materials d. Communication skills training e. Training in interpretation of patient- supplied information f. Materials on interpretation of patient-supplied information g. Other: _____ 	<p>D. Method of intervention (circle all that apply):</p> <ul style="list-style-type: none"> i. Patient: <ul style="list-style-type: none"> a. Patient-reported health instrument b. Other questionnaire c. Checklist d. Educational materials e. One-to-one coaching f. Group education g. Other: _____ ii. Provider: <ul style="list-style-type: none"> a. Prompt list b. Provider checklist c. Educational materials d. Communication skills training e. Training in interpretation of patient- supplied information f. Materials on interpretation of patient-supplied information Other: _____

<p>E. Brief description of intervention tools listed above:</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>E. Brief description of intervention tools listed above:</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>E. Brief description of intervention tools listed above:</p> <p>_____</p> <p>_____</p> <p>_____</p>
<p>F. Method of delivery of patient intervention (circle all that apply):</p> <p>i. Mailed</p> <p>ii. In clinic</p> <p> a. Computerized</p> <p> b. Written</p> <p> c. Video</p> <p> d. Face-to-face</p> <p>iii. Telephone</p> <p>iv. Community-based</p> <p>v. Other: _____</p>	<p>F. Method of delivery of patient intervention (circle all that apply):</p> <p>i. Mailed</p> <p>ii. In clinic</p> <p> a. Computerized</p> <p> b. Written</p> <p> c. Video</p> <p> d. Face-to-face</p> <p>iii. Telephone</p> <p>iv. Community-based</p> <p>v. Other: _____</p>	<p>F. Method of delivery of patient intervention (circle all that apply):</p> <p>i. Mailed</p> <p>ii. In clinic</p> <p> a. Computerized</p> <p> b. Written</p> <p> c. Video</p> <p> d. Face-to-face</p> <p>iii. Telephone</p> <p>iv. Community-based</p> <p>v. Other: _____</p>
<p>G. Patient information fed back to providers?</p> <p>i. Yes</p> <p> a. Format (choose one):</p> <p> 1. Raw data</p> <p> 2. Interpreted data</p> <p> • Details: _____</p> <p> b. Provided to (choose all that apply):</p> <p> 1. Physician</p> <p> 2. Nurse</p> <p> 3. Other: _____</p> <p> c. Method of delivery:</p> <p> 1. Mailed</p> <p> 2. In clinic:</p> <p> • Written</p> <p> • Computerized</p> <p> 3. Other: _____</p> <p>ii. No</p>	<p>G. Patient information fed back to providers?</p> <p>i. Yes</p> <p> a. Format (choose one):</p> <p> 1. Raw data</p> <p> 2. Interpreted data</p> <p> • Details: _____</p> <p> b. Provided to (choose all that apply):</p> <p> 1. Physician</p> <p> 2. Nurse</p> <p> 3. Other: _____</p> <p> c. Method of delivery:</p> <p> 1. Mailed</p> <p> 2. In clinic:</p> <p> • Written</p> <p> • Computerized</p> <p> 3. Other: _____</p> <p>ii. No</p>	<p>G. Patient information fed back to providers?</p> <p>i. Yes</p> <p> a. Format (choose one):</p> <p> 1. Raw data</p> <p> 2. Interpreted data</p> <p> • Details: _____</p> <p> b. Provided to (choose all that apply):</p> <p> 1. Physician</p> <p> 2. Nurse</p> <p> 3. Other: _____</p> <p> c. Method of delivery:</p> <p> 1. Mailed</p> <p> 2. In clinic:</p> <p> • Written</p> <p> • Computerized</p> <p> 3. Other: _____</p> <p>ii. No</p>

<p>H. Total intervention time: # hours: ___ / # minutes: _____ Detail: _____</p>	<p>H. Total intervention time: # hours: ___ / # minutes: _____ Detail: _____</p>	<p>H. Total intervention time: # hours: ___ / # minutes: _____ Detail: _____</p>
<p>I. Time of intervention delivery in relation to consultation (<i>choose one</i>):</p> <ol style="list-style-type: none"> i. Immediately pre-consultation ii. ___ (#) days before consultation iii. ___ (#) weeks before consultation iv. Not reported v. Not applicable vi. Other: _____ 	<p>I. Time of intervention delivery in relation to consultation (<i>choose one</i>):</p> <ol style="list-style-type: none"> i. Immediately pre-consultation ii. ___ (#) days before consultation iii. ___ (#) weeks before consultation iv. Not reported v. Not applicable vi. Other: _____ 	<p>I. Time of intervention delivery in relation to consultation (<i>choose one</i>):</p> <ol style="list-style-type: none"> i. Immediately pre-consultation ii. ___ (#) days before consultation iii. ___ (#) weeks before consultation iv. Not reported v. Not applicable vi. Other: _____
<p>J. Additional description of intervention:</p> <p>_____</p> <p>_____</p>	<p>J. Additional description of intervention:</p> <p>_____</p> <p>_____</p>	<p>J. Additional description of intervention:</p> <p>_____</p> <p>_____</p>

K. Description of control group activities: _____

L. Total control activity time:
hours: ___ # minutes: _____
Details: _____

M. Were groups treated equally (aside from intervention)?

- i. Yes
- ii. No

V. **RESULTS MEASUREMENT**

A. Results (<i>circle one per row</i>)	B. Detail	C. Measurement method (<i>circle all that apply</i>):	D. Assessment tool used	E. Effect of intervention (<i>choose all measurement times reported; for each time, circle one effect</i>)
i. Communication ii. Patient involvement in decision-making iii. Patient self-efficacy iv. Patient anxiety v. Patient adherence vi. Patient health status vii. Patient QoL viii. Patient satisfaction ix. Decisional conflict x. Other:		i. Observer-assessed ii. Patient-reported iii. Provider-reported iv. Medical records Extraction v. Physical exam vi. Laboratory test vii. Other: <i>For (i), (iv), (v), and (vi) were assessors blinded?</i> <input type="radio"/> Yes <input type="radio"/> No		i. Results measured immediately after the consultation/ used audiotape or videotape a. Positive effect b. Negative effect c. No effect ii. Results measured ___ (#) weeks after consultation a. Positive effect b. Negative effect c. No effect iii. Results measured ___ (#) months after consultation a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect
i. Communication ii. Patient involvement in decision-making iii. Patient self-efficacy iv. Patient anxiety v. Patient adherence vi. Patient health status vii. Patient QoL viii. Patient satisfaction ix. Decisional conflict x. Other:		i. Observer-assessed ii. Patient-reported iii. Provider-reported iv. Medical records Extraction v. Physical exam vi. Laboratory test vii. Other: <i>For (i), (iv), (v), and (vi) were assessors blinded?</i> <input type="radio"/> Yes <input type="radio"/> No		i. Results measured immediately after the consultation/ used audiotape or videotape a. Positive effect b. Negative effect c. No effect ii. Results measured ___ (#) weeks after consultation a. Positive effect b. Negative effect c. No effect iii. Results measured ___ (#) months after consultation a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect

A. Results (<i>circle one per row</i>)	B. Detail	C. Measurement Method (<i>circle all that apply</i>):	D. Assessment Tool Used	E. Effect of intervention (<i>for each result measurement circle one effect</i>)
i. Communication ii. Patient involvement in decision-making iii. Patient self-efficacy iv. Patient anxiety v. Patient adherence vi. Patient health status vii. Patient QoL viii. Patient satisfaction ix. Decisional conflict x. Other:		i. Observer-assessed ii. Patient-reported iii. Provider-reported iv. Medical records Extraction v. Physical exam vi. Laboratory test vii. Other: For (i), (iv), (v), and (vi) were assessors blinded? <input type="radio"/> Yes <input type="radio"/> No		i. Results measured immediately after the consultation/ used audiotape or videotape a. Positive effect b. Negative effect c. No effect ii. Results measured ___ (#) weeks after consultation a. Positive effect b. Negative effect c. No effect iii. Results measured ___ (#) months after consultation a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect
i. Communication ii. Patient involvement in decision-making iii. Patient self-efficacy iv. Patient anxiety v. Patient adherence vi. Patient health status vii. Patient QoL viii. Patient satisfaction ix. Decisional conflict x. Other:		i. Observer-assessed ii. Patient-reported iii. Provider-reported iv. Medical records Extraction v. Physical exam vi. Laboratory test vii. Other: For (i), (iv), (v), and (vi) were assessors blinded? <input type="radio"/> Yes <input type="radio"/> No		i. Results measured immediately after the consultation/ used audiotape or videotape a. Positive effect b. Negative effect c. No effect ii. Results measured ___ (#) weeks after consultation b. Positive effect b. Negative effect c. No effect iii. Results measured ___ (#) months after consultation a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect

- F. Was an intention-to-treat analysis performed?
- i. Yes
 - ii. No/Not reported

Appendix III: Results of electronic search strategies

Search	Titles returned (N)	Abstracts reviewed (N)	Articles retrieved in full (N)	Articles included (N)
<i>Main</i>	3090	495	132	70
<i>Patient-reported outcome measures</i>	2082	162	28	22
<i>Individualised measures</i>	710	37	5	3
<i>Pain assessment</i>	239	21	5	4
<i>Patient-held records</i>	42	7	6	0
<i>Self-management/ goal-setting</i>	1396	494	17	6

Appendix IV: Included studies

	Author	Year	Country	Intervention Method
1.	Albertson et al	2002	US	questionnaire
2.	Alexy	1985	US	questionnaire, goal setting
3.	Anderson et al	1987	US	video modeling
4.	Ayana et al	2001	UK	patient held record
5.	Barrera et al	2002	US	coaching, goal setting
6.	Berry et al	1989	US	coaching, group ed, goal setting
7.	Billault et al	1995	France	patient held record
8.	Brody et al	1990	US	PROM, questionnaire, provider ed. materials
9.	Brown, Bolesse et al	1999	US	provider training
10.	Brown, deNegri et al	2000	Honduras	provider training
11.	Brown, Butow et al	1999	Australia	checklist, coaching
12.	Brown, Butow et al	2001	Australia	checklist, other provider intervention
13.	Bruera et al	2003	US	checklist
14.	Butow et al	1994	Australia	checklist
15.	Calkins et al	1994	US	PROM
16.	Callahan et al	1996	US	PROM
17.	Camp-Sorrell et al	1991	US	provider prompt list
18.	Cegala et al	2001	US	ed. materials, coaching, checklist
19.	Cegala et al 2000; Cegala and Post et al 2000; Post et al 2001		US	Ed. Materials
20.	Clark et al; Hampson et al	2004	UK	questionnaire, goal setting
21.	Cope et al	1986	US	provider training
22.	Davison et al	1997	Canada	Coaching
23.	Delvaux et al	2004	Belgium	provider training
24.	Detmar et al	2002	Netherlands	PROM
25.	Didjurgeit et al	2002	Germany	other patient intervention
26.	Dolan et al	2002	US	values clarification
27.	Dow et al	1991	US	group education
28.	Dowrick; Dowrick and Buchain	1995	UK	PROM
29.	Drury et al	2000	UK	patient held record
30.	Edwards et al	2004	UK	provider training
31.	Evans et al	1987	Australia	provider training, provider ed. materials
32.	Fallowfield et al	2002	UK	provider training, individual feedback re: communication skills

33.	Faries et al	1991	US	patient questionnaire, provider prompt list
34.	Feuerstein et al	1989	US	questionnaire
35.	Fleissig et al	1999	UK	checklist
36.	Ford et al	1995	UK	other patient intervention
37.	Frederikson et al	1995	UK	ed. materials
38.	Friedman et al	1996	US	other patient intervention
39.	Gagne et al	2003	US	goal setting
40.	Gater et al	1998	UK	PROM
41.	Glasgow et al	2003	US	coaching, goal setting
42.	Goel et al	2001	Canada	values clarification
43.	Gold et al	1989	US	PROM
44.	Goldsmith et al	1989	US	PROM
45.	Greco et al	1998	UK	provider training
46.	Greenfield et al	1988	US	coaching
47.	Greenfield et al	1985	US	coaching
48.	Hack et al	2003	Canada	other patient intervention
49.	Hagopian et al	1990	US	other patient intervention
50.	Hershey et al	2002	US	PROM
51.	Hoeper et al	1984	US	PROM
52.	Hornberger et al	1997	US	questionnaire
53.	Inui et al	1979	US	questionnaire
54.	Jenkins et al	2002	UK	provider training
55.	Johnstone et al	1976	UK	PROM
56.	Joos et al	1996	US	patient questionnaire, provider training
57.	Kaplan et al	1989	US	coaching
58.	Kazis et al	1990	US	PROM
59.	Kennedy et al	2002	UK	values clarification
60.	Kidd et al	2004	UK	coaching, ed. materials
61.	Kim et al	1992	Nigeria	provider training
62.	Kim et al	2003	Indonesia	coaching
63.	Kinmonth et al	1998	UK	patient ed. materials, provider training
64.	Kutner et al	1999	US	questionnaire
65.	LaFerriere et al	1978	US	provider training, goal setting
66.	Lecouturier et al	2002	UK	patient held record
67.	Lester et al	2003	UK	patient held record
68.	Levinson et al	1993	US	provider training
69.	Lewis et al	1996	UK	PROM
70.	Linn et al	1980	US	PROM

71.	Magruder-Habib et al	1990	US	PROM
72.	Maly et al	1999	US	checklist
73.	Martinali et al	2001	Netherlands	checklist
74.	Mate-Kole et al	1999	Canada	goal setting
75.	Mathias et al	1994	US	PROM
76.	McCann et al	1996	UK	ed. materials
77.	McGee et al	1998	US	coaching
78.	McLachlan et al	2001	Australia	PROM
79.	McLean et al	2004	UK	provider prompt list
80.	Montgomery et al	2003	UK	values clarification
81.	Moore et al	1978	US	PROM
82.	Moral et al	2001	Spain	provider training
83.	O'Connor et al	1999	Canada	values clarification
84.	O'Connor et al	1998	Canada	values clarification
85.	Olivarius et al	2001	US	provider prompt list
86.	Oliver et al	2001	US	coaching, questionnaire, ed. materials
87.	Pill et al	1998	UK	provider training
88.	Pruyn et al	2004	Netherlands	checklist
89.	Putnam et al	1988	US	provider training
90.	Radecki et al	1999	US	questionnaire
91.	Rand et al	1988	US	PROM
92.	Ravaud et al	2004	France	PROM, provider prompt list
93.	Reifler et al	1996	US	PROM
94.	Robbins et al	1979	US	provider training
95.	Robinson et al	1985	UK	ed. materials
96.	Ross et al	2004	US	patient held record
97.	Rost et al	1991	US	coaching, ed materials
98.	Roter et al	1998	Trinidad and Tobago	provider training
99.	Roter	1984	US	coaching
100.	Roter et al	1995	US	provider training
101.	Rothert et al	1997	US	values clarification
102.	Rubenstein et al	1995	US	PROM
103.	Rubenstein et al	1989	US	PROM, provider training
104.	Ruland et al	2003	US	questionnaire
105.	Ruland	2002	Norway	values clarification
106.	Ruland	1999	US	values clarification
107.	Saitz et al	2003	US	PROM

108.	Schriger et al	2001	US	PROM
109.	Scott et al	1999	UK	provider training
110.	Sepucha et al	2000	US	other patient intervention
111.	Sepucha et al	2002	US	questionnaire, coaching
112.	Shapiro et al	1987	US	PROM
113.	Smith et al	1995	US	provider training
114.	Street et al	1994	US	PROM
115.	Tabak	1988	US	ed. materials
116.	Taenzer et al	2000	Canada	PROM
117.	Tennstedt	2000	US	group education
118.	Theunissen et al	2003	Netherlands	provider training
119.	Thom et al	1999	US	provider training
120.	Thompson et al	1990	US	ed. materials
121.	Thompson et al	1985	US	checklist, ed. materials
122.	Tobacman et al	2004	US	patient held record
123.	Trowbridge et al	1997	US	PROM
124.	Van Os et al	2004	Mixed European	checklist
125.	van Roosmalen et al	2004	Netherlands	values clarification
126.	Velikova et al	2004	UK	PROM
127.	Wagner et al	1997	US	PROM
128.	Wasson et al	1992	US	PROM
129.	Wasson et al	1999	US	PROM, ed materials
130.	Weatherall	2000	New Zealand	PROM
131.	White et al	1995	UK	PROM
132.	Wilkinson et al	2002	US	ed. materials
133.	Williams et al	2001	UK	patient held record
134.	Williams et al	1999	US	PROM, questionnaire
135.	Wressle et al	2002	Sweden	goal setting
136.	Yager et al	1981	US	PROM
137.	Zung et al	1983	US	PROM
